

Medicaid Reform for People with Disabilities

A Guide for Legislators

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The Missouri Planning Council for Developmental Disabilities is a federally funded, 23-member, consumer-driven council appointed by the Governor. The Council's mandate is to plan, advocate for, and give advice concerning programs and services for persons with developmental disabilities that will increase their opportunities for independence, productivity, and integration into communities.

People First of Missouri is a statewide self-advocacy organization formed by, run by and which exists for persons with disabilities. Currently, there are over 40 chapters across the state of Missouri with over 1,000 members. People First of Missouri promotes equality for people with disabilities so they can live the life they want in the community.

Medicaid is the largest provider of healthcare and long-term supports in the community for low-income individuals with developmental disabilities. Transformation of that system should contain some essential aspects in order to be responsive to the needs of individuals with developmental disabilities. This document contains the recommendations from the Missouri Planning Council for Developmental Disabilities and People First of Missouri for the transformation of Missouri's state-sponsored health insurance program currently known as Medicaid.

The institutional bias in state-sponsored health insurance that forces individuals into nursing homes and other congregate facilities needs to end.



Currently, individuals in need of some services or medical equipment can only receive them in an institutional setting. The need for a single piece of equipment or service could force an individual into a facility, when they could otherwise remain in their home if that same service or equipment were covered in the community.



The 1999 Olmstead Decision requires that states provide services in the most integrated setting. Living in the community with the necessary supports is evidence based best practice, increases quality of life for individuals with disabilities and often costs less than institutional living. People must have the supports necessary to remain in their own home and transition from congregate institutional settings to individualized community settings.

RECOMMENDATIONS

Any reform to the state's health insurance system must keep the unique needs of individuals with developmental disabilities in mind.

Individuals with developmental disabilities must have access to the same preventative care, diagnostic expertise and treatment as any other citizen. The life of an individual with a disability is as important and valuable as that of any other.

People with developmental disabilities may require specialized services to live in the community, assure quality of life, prevent unnecessary pain and suffering, and protect the progress they have made through therapy and medical care.

Providers must gain knowledge about developmental disabilities and make medical decisions or provide care options in collaboration with the individual that make sense for the individual.

"Pay for performance" reimbursement systems must not penalize individuals with developmental disabilities or the professionals who provide their care since many of their conditions cannot be cured. This has the potential to discourage providers from serving individuals with lifelong conditions.

RECOMMENDATIONS

Reward systems must not penalize people with developmental disabilities by disregarding their individual abilities. For example, earning medically necessary care, such as a dentist visit, as a reward for exercising may be an unacceptable premise for an individual with limited mobility.

Medical care, treatment and equipment should never be used as an incentive for compliance.

Patient education and preventative care should recognize the individual needs and unique learning styles of individuals with disabilities. Only then should the expectation of preventative action and personal responsibility be in place.

Choices for medical care and treatment afforded to every other citizen must be available for individuals with developmental disabilities. Individuals are capable of and should be allowed to choose their healthcare or service provider. No treatment, provider, physician, medication or device should be forced on any individual.

RECOMMENDATIONS

Dental, personal care, podiatry, rehabilitation, and specialty care including medical equipment and other services identified as optional by the Centers for Medicaid and Medicare, must be covered.



These services are essential to an individual's health and quality of life. These services increase independence. Denying these essential services moves people toward costly and unnecessary institutional care.

Any provision or rule created, changed, or that currently exists, should have an appeals/exception process that takes into account an individual's unique needs, choices and circumstances, is person-centered, expeditious and easy to navigate.

RECOMMENDATIONS

The transformation process should be completely transparent.



Any changes should be discussed and decided publicly. Individuals who use Medicaid should be considered experts. They should be sought out for input and their recommendations used to craft and implement a system that works for them.

Reimbursements to doctors and dentists should be fair.



Doctors and dentists should be widely available to patients in all areas of the state. Individuals should have choice when it comes to their health care provider. In order for doctors and dentists to voluntarily participate in a state sponsored health insurance program, reimbursement must be an incentive, not a disincentive. Medicare reimbursement rates should be used as a guide.

RECOMMENDATIONS

Workers with disabilities should have the opportunity to buy into a state-sponsored health insurance plan. The buy-in rate should be reasonable for the cost of the plan.



Individuals with disabilities want to work, accept personal responsibility, and contribute to their living expenses. Healthcare access should not be a barrier to obtaining community employment. People should not have to choose between having necessary healthcare and contributing through meaningful employment. Parameters for a ‘workers with disabilities’ program should not be so restrictive that it limits an individual’s career options or prohibits work entirely. Any buy-in program for workers with disabilities must be fair and equitable for persons in community based employment and should not contain a “bias” for those employed in sheltered employment or other segregated settings.

RECOMMENDATIONS

The current Spend-Down Program must be reformed.



The spend-down philosophy needs to be reformed from forcing people into poverty to a premium-based approach to encourage productivity and growth. An individual or family should not have to choose between healthcare and other basic necessities. Expenditures for health insurance should be affordable and premium-based, depending on income.

The eligibility limit should be raised to at least 100% of Federal Poverty Level. Only individuals above 100% of the FPL should participate in cost-sharing. Cost-sharing should be based on a percentage of their income, with an absolute limit.



Those individuals above 100% of the FPL should cost-share based on a sliding scale as a percentage of their net income. Individuals and families who do not have access to affordable health insurance should have the opportunity to participate in a state sponsored health insurance plan that meets their needs.

RECOMMENDATIONS

 Asset limits need to be at least \$2,500 for an individual and \$5,000 for a couple. This would allow individuals with disabilities to be able to cope with an unexpected emergency, bill, necessary purchase or to save for a home or car down payment.

Expand home and community-based services to individuals with developmental disabilities.

 We support the ideas brought forth in Appendix A, Option 6.5 and 6.6 of the document entitled "The Transformation of Missouri Medicaid to MO HealthNet: Recommendations Offered by the Departments of Social Services, Health and Senior Services and Mental Health" released December 7th, 2006. Either through redesign or development of waivers, home and community based services should be expanded and made widely available to prevent institutional placement and transition individuals from congregate settings to the community.

Medicaid and mental health transformation must go hand-in-hand to prevent cost shifting from one system to the other.

RECOMMENDATIONS

 *No person with a developmental disability should be uninsured.*

 In many cases private insurance is not available for people with developmental disabilities at any cost. In other cases, it is not affordable or does not provide the services that the individual needs. In those cases, state sponsored health insurance should be available.